Unmet needs in Cushing's syndrome: the patients' perspective

Summary of journal article: Valassi, E., et al. (2022). Endocrine Connections, 11(7), e220027.

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Researchers look at the results of many studies to better understand a disease like Cushing's syndrome. This summary shows the results of one study. Other studies may find different results.

01 WHAT

Is the background to this study?

Cushing's syndrome (or CS) is a condition that is caused by an increased level of a hormone called cortisol in the body.

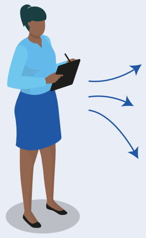
This is usually the result of a tumor on the pituitary gland in the brain, or a tumour on the adrenal gland above the kidneys, or an ectopic tumour (a tumour that occurs outside of the pituitary and adrenal glands).

Common symptoms of CS include weight gain, a build-up of fat around the torso, neck, and shoulders (but not on the arms and legs), a red puffy face, easily bruised skin, and depression and mood swings. These symptoms can be incredibly burdensome for patients and may lead to other problems like high blood pressure, heart disease, and diabetes. Left untreated, CS is associated with an increased risk of death and a decrease in patient quality of life.

Little is known about patients' experiences and perceptions of the medical journey from their first symptoms to diagnosis, treatment, and follow-up.

Did the researchers measure?

Patients filled in a survey asking several different questions, including questions related to…



- **Time from first symptoms to diagnosis**
- **Persistent symptoms after treatment**
- **Most burdensome symptoms**

The survey was designed by a group of CS experts and was sent out to patients via the following patient organisations: World Association for Pituitary Organisations, Adrenal Net, Cushing's Support & Research Foundation, Pituitary Foundation, China Hypercortisolism Patient Alliance, and was also distributed to local patient associations.

Another survey was sent to doctors asking about their experience of the diagnosis, symptoms and treatment of patients with CS. Responses from the patient and doctor surveys were compared.

02 WHY

Was this study done?

- **To learn about patients' experiences of living with CS, including information about initial symptoms, diagnosis, treatments, and what happened after treatment**
- **To learn about the experience and opinions of doctors that work closely with CS patients**

03 WHO

Took part in the study?

320 CS patients

88% Female

12% Male

69% from Europe

19% from US

40 Doctors

83% Endocrinologists

Most from Europe

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04 WHAT

Were the main results?

There was a delay in diagnosis for a large percentage of patients

Almost **50%** of patients were diagnosed after 2 years from first symptoms

The most burdensome symptoms reported by patients were:

1. **Weight gain**
2. **Hirsutism and acne**
3. **Fatigue**

Symptoms remain, even after the treatment of CS, including…

Fatigue

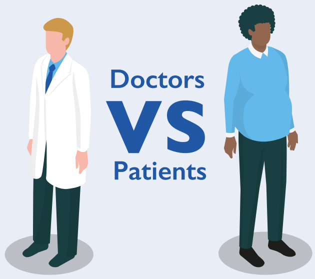
Muscle weakness

Weight gain

Many symptoms are undertreated, suggesting inadequate follow-up by specialist doctors.

Doctors and patients had different perspectives on how often patients experience some symptoms, both during active disease and also after treatment

For example, doctors underestimated how often patients experience obesity/weight gain and depression/mood problems



05 HOW

Can this summary help patients talk with healthcare professionals?

Healthcare professionals
How can this research help me care for patients?

Patients
Is this research relevant for what matters to me?

06 WHO

Sponsored this study?

The study was sponsored by a company called HRA Pharma Rare Disease, 200 avenue de Paris, 92320 Châtillon, France

More information

The original study report was published online in June 2022, and can be accessed at the following link:

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